

Public Health Committee
Connecticut General Assembly
March 1, 2016
Testimony related to S. B. 294

Senator Gerratana, Representative Ritter and members of the Public Health Committee,

Thank you for raising S.B. 294. This bill is important to my family because I have a 22 year old special needs child receiving DDS services who still lives at home with me. He has been on the residential waiting list for four years. I was under the (mis)impression that it was truly a waiting list and his turn would come within a few years if we were patient. It's unfathomable to me that the 'waiting list' for day and residential supports are ambiguous and unpredictable (and dare I say unreliable) for our most vulnerable citizens.

My son Michael has intellectual and developmental disability and autism, requiring 24/7 care. He is ambulatory but has limited verbal capabilities. I am fortunate to be in my late 40s and in good health... Michael has always been a very welcome and essential part of our family life. However, there is a looming reality that he will need support long after I am gone. As many parents of special needs children I have accepted the fact that retirement isn't on the horizon for me and Michael will likely be in my care for my lifetime. However, it scares me not to have a solid plan for the day I am no longer able to physically care for him. Residential placement will be a critical piece of this puzzle.

I respectfully request that some changes be made to the proposed bill:

- 1) Remove the word, 'urgent' from the waiting list characterization as the waiting list should not be reserved for emergency placements only.
- 2) Modify the notification procedures for waiting list status from every 3 years to annually, allowing input to consider the family/caregiver's changing needs.
- 3) Amend the bill so that individuals and families requesting services or increase in supports from DDS be provided with copies of the documents used by DDS that formed the basis for its decision.
- 4) Maintain separate waiting lists for day and residential supports so DDS can be afforded autonomy to best serve those in need.

As Michael's mother, legal guardian, and advocate, it's my job to ensure he has every opportunity to live to his potential. S.B. 294 gives me hope that his voice, and that of the others in the special needs community, will be heard. Thank you for your efforts on behalf of all of the citizens and taxpayers of Connecticut. Please do not hesitate to contact me with any questions.

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